

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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Non Hispanic white, Higher Education

Baltimore, Maryland

Moderator: Wendy Child

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTH CARE

I. Prevention

Participants mentioned the following as diseases they are most concerned about:

- Chicken pox
- Diseases that cannot be prevented such as cancer or spinal meningitis
- Diseases that were “wiped out” but are coming back, such as whooping cough and tuberculosis

Comments included:

I've heard where there are diseases that are coming back that have been supposedly wiped out...That kind of alarms me because a doctor might not see it for awhile and just misdiagnose it and then end up with some kind of tragic ending...

The kind of things that really upset me...[are] more the things that they don't have any control over like spinal meningitis or something like that. If that comes, there's just not much they can do. That's really scary to me.

II. Immunization

A. *Reasons not to get vaccinated*

- Religious objections
- Concern about side effects from vaccines such as chicken pox and polio vaccines
- Allergies that affect safety of some vaccines for particular children
- Denial about the importance of preventive health care
- Affordability or not knowing about free sources for vaccinations

B. *Reasons to get vaccinated*

- School or daycare requirement
- To protect your children and the children or other people that they come in contact with
- It is a parental responsibility
- To show your children that you care
- Doctor's recommendation

Comments included:

It is almost a social type of thing because you not only got the children, you've got your parents, grandparents, and one little cold that the child might have come across might get passed down and turn into something worse. I guess chicken pox I heard could be bad for older people.

One reason is to show the kids that I care. Before they get the shot...I try to explain what the shot is for and why they have to do it and yes, it's going to hurt, but you know it's because I love them and I care for them, so I want to say it's a caring thing. The second thing is that I love my pediatrician...He said, 'I gave [the chicken pox vaccine] to my grandson so if it's good enough for my grandson, it's good enough for your daughter'...I have a lot of faith in my pediatrician.

C. Ways parents are reminded of vaccine schedule

- Doctor's office schedules visits to coincide with recommended vaccinations
- During doctor visits
- Notices from school or daycare
- Record card that doctor's office fills out for parents

D. Methods of easier tracking

- If doctor's office could photocopy medical record instead of copying information into parents' record card
- Provide parents with a durable card that could be punched or stamped each time a child receives a particular vaccination instead of having blanks to fill in manually

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

- Participants voiced more concerns or reservations than benefits in their initial reactions. Concerns included: invasion of privacy, scope of the information to be included (e.g., just immunization information or other medical data), potential inaccuracies in the information, children mistakenly getting repeat immunizations, cost, and whether someone might have access who could use the information to discriminate (e.g., such as an employer who finds out that your child has an illness.) Only a few people cited potential benefits.

Comments included:

I think potentially it's a good idea, at least from my experience working with city families. They live a rough life to begin with and they're very transient. They don't know what doctor they see because they're always going to clinics...I think it would be helpful for them. [Not having vaccinations] keeps kids out of school a long time...On the other hand, I see the privacy issue and information being misused. Is it accurate? Is it going to be updated? Can we rely on it?

In general, I don't like any type of registry. I think it does invade your privacy and it can be used. It's easy to say that people can't get to it and it won't be generally available,

but we all know that there are some people who if they want something, they'll get it...Perhaps it could be something that's voluntary. People would know going into it what would be involved...let them volunteer for it.

...My initial reaction was 'who's going to pay for it?' How do you protect the data?...A medical doctor isn't qualified to enter data...My first reaction would be lots of questions of how to design it...I think it's a neat idea, but...it's not enough information to form an opinion.

My initial reaction was that I think it would be a good idea, but the privacy thing is one concern and just how it would work...Depending on who gets access to it, you would have to worry about whether your employer is seeing what's wrong with your kid. Because a lot of employers provide medical benefits and if your kids have problems, is that going to affect you being hired or fired?

I initially thought it was a good idea. I think it would be good to tap into this record, not now, but at a later time you may need that information if the child is going to a different school, it would be easy to get it that way. Or if your pediatrician's office has gone out of business...I don't have a problem with the privacy. There isn't much that people could do with the information...as long as it's just the immunization material.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Participants' initial reactions were mostly positive, especially about the inclusion of the manufacturer and lot number of vaccines
- A few participants seemed concerned about the inclusion of mother's maiden name because it is used so often as a security code for credit accounts.

Comments included:

Sometimes there are problems with batches of vaccines so [the registry] might be a good way to pull people up who got what. If there's a problem, they can monitor the people who had gotten that particular lot...So, it would be helpful.

Originally, I was concerned with the privacy...but now that I see it's going to be very limited information, then I'm not as concerned.

My initial reaction...it seems harmless, but if I think about it, I probably could find reasons why I wouldn't want it done.

B. Reactions to including home address and phone number

- Participants did not voice strong opinions about this. One person was concerned that addresses could become obsolete more quickly than other identifying information. One person suggested that perhaps the date and place of birth could be used to code the information. Another suggested that the name of the doctor who administered the vaccine could be used for tracking people.

C. Reactions to including parent or child Social Security number

- Reactions to the possible inclusion of a Social Security number were mixed. One participant thought that something like a Social Security number would help to avoid confusion if some people have similar names. A benefit to including parent's Social Security numbers would be not having to remember or find several children's numbers to access their vaccination records. Other people were concerned that the Social Security number would facilitate access to other medical and financial data if someone obtained it.

Comments included:

I'm glad the Social Security number is not going to be there.

Social Security [numbers]: that's your ticket to everything if someone gets a hold of it...those numbers can be like a fire bomb going off. You have to be very, very delicate working with people, especially children.

D. Reactions to including healthcare members enrollment identification (WIC, Medicaid numbers)

- Participants were mostly opposed to including this information.

Comments included:

That's a privacy issue.

It just wouldn't be right.

Why should you label them and not everybody else?

It's a form of discrimination.

III. Access

A. Who should have access

Participants identified the following as appropriate for having access, but comments revealed that not everyone agreed with these:

- Hospitals
- Health departments
- School systems
- Doctor's office

Comments included:

It might be a big help for the schools, instead of tracking down everything, they go right to the computer and get all the information.

I would rather have, if it's not me saying [to someone] 'Yes, you have the authority to access the information,' then I want to have her pediatrician give that authority. I don't think that the schools need it...

I imagine the doctor's office [should have it], but I would be concerned about who's going to be putting the information into the registry and whether they're trained...

I think it's kind of a waste of resources for the school to have the information...there's got to be a better way to do this. You need a trained individual to access it.

B. Who should not have access

- Employers
- Government
- Insurance companies

Comments included:

I still have concerns that all government agencies should have access to something like this...Look at the political situation today. They dig up absolutely everything about people and use it against them...Maybe [insurance companies] shouldn't have access to it either because maybe they won't give somebody health care if they see there are certain things in the record they don't like for some reason.

C. Reactions to the idea of linking registry by computer to other health information systems

- Most participants reacted fairly positively to this idea. Comments included:

It's just a phenomenal medical research tool. Think of the medical advances or the medical research that's going on that could be helped with this kind of data...that's a real big benefit.

Maybe there could be some way those type of registries could access it but not get the personal information, but they could still use the medical information.

IV. Consent and inclusion

A. Reactions to "opting out" option

- Initial reactions included questions about how long parents would have to opt out and in what way (such as by an 800 number); who would be sending the information, how the information gets into the registry in the first place, whether the doctor is releasing the information. Only a few people voiced specific objections.

Comments included:

I don't like this situation because I think...it puts you out if you don't want to be in it...it's passive. If it's set up where we have to give consent from the get-go...it's more active. To me, it's more honest.

Isn't there quite a bit of information that doctors already give out without your consent because they are required to by law?

B. Reactions to “consent” option

- Several participants preferred this option over the others even though they also said that the opt out option would be easier for states to manage and would result in more people being included in the registry.
- Participants raised questions about whether doctors will be required to furnish this information or whether they will be compensated for providing it; whether parents will be able to check the accuracy of information.

Comments included:

I think the option I prefer is mainly getting your permission to put it in. When they get your permission, they should also tell you why they want that information, so you would be more informed about what's going on with it.

I like the [consent] option best also...with opting out, you have the problem of people who never reply and say, 'Well, wait. I never got that.

I would prefer the consent option, but I can understand why the state...would do the opt out program. They have that here with the Motor Vehicle Administration where if you don't want your records to go out, you have to tell them you don't.

C. Reactions to “automatic” option

- Only one participant supported this option. She said that she would actually prefer to provide consent, but said:

If everybody's doing it, who cares if I had the choice?

SECTION 3: WRAP-UP AND CLOSING

I. Most important benefits of registries

- The registry will aid research
- Getting children into school and daycare on time
- Having a record in later years
- Being able to notify and treat people who were vaccinated from a bad lot

II. Greatest concerns/biggest risks

- Privacy
- Possibility of incomplete or inaccurate information
- Too few people in the system if participation is not compulsory
- Cost to taxpayers

Comments about concerns included:

If you allow people to opt out, what good is it? You have information about 50 percent of the population. If you make it compulsory, then...that's your privacy issue. I don't see what the point is of making a registry that's voluntary and I'd like to find other registries like lead poisoning...that are voluntary and see if those are worthwhile.

The privacy issue would be a concern. I guess we shouldn't act like we're all paranoid or anything like that but when you see shows that tell you [what can be done with information about you...] I mean I can see how it's a benefit for the schools...[but] it has to benefit some kind of research too – medical research. If it's just a vaccination registry, I can't see creating this whole bureaucracy.

I'm concerned a little bit with the cost of putting this all together. It's all going to come down to the taxpayer. This information will be useful. If there is enough information to be useful for research, I'm for that.

III. Influence of healthcare provider in decision to participate in a registry

[This topic was added to the discussion guide after this group.]

IV. Suggestions/comments to people who are responsible for how system works

- Participants' closing suggestions and comments included:

Keep in mind the privacy issues, who would pay for it, how it would be administered. It would be important to educate people on what would be the uses [of the information]...I don't think it should be forced by the government. Find out what people really think and let them decide if it will be useful...

Overall, it's a good idea. I need more information on the what, where, and when...

What are the benefits to having a registry and how would the information be used. The main thing is what is the cost involved and who's going to pay for it? I think more information needs to be gathered before making a strong opinion for or against a registry and right now, I'm in the middle.

[There should be] a well thought out goal about the purpose...and then the cost analysis. How much benefit are we going to get out of the cost...who's going to maintain it and be responsible for it?

I feel very strongly [about the need] to look at existing precedents. What information is out there about you that you can't opt out of. Like your credit report...do a thorough analysis.